

# The limits of parental power in health decisions relating children – guidelines

Délio José Kipper

## Abstract

Respect for human beings is one of the fundamental principles of bioethics, and is manifested through the exercise of autonomy. When a patient is not competent to make decisions regarding his or her health, as is the case with children under twelve years of age, there is a presumption that parents should make decisions on behalf of the child through the exercise of parental authority. The present study discusses the legitimacy and judicial right of parents to make decisions for their children when the choices involved go beyond the boundaries permitted by ethics, law and society. The study also considers common practice in Brazil, when there is a conflict of interest between the treatment proposed by the medical professional and the wishes of parents.

**Keywords:** Bioethics. Decision-making. Parenting. Ethical analysis. Legislation.

## Resumo

### Limites do poder familiar nas decisões sobre a saúde de seus filhos – diretrizes

O respeito pelo ser humano é um dos princípios fundamentais da bioética, que se manifesta no exercício da autonomia. Quando o paciente não tem competência para tomar suas próprias decisões em relação à saúde, como no caso de crianças com menos de 12 anos, há a presunção de que seus pais decidem por elas, no exercício do poder familiar. O que queremos discutir é a legitimidade e a justiça dessa decisão, quando suas opções ultrapassam os limites tolerados pela ética, pela lei e pela sociedade em determinadas situações, e qual é a prática usual no Brasil quando há conflito de interesses entre a proposta terapêutica do médico e o desejo dos pais.

**Palavras-chave:** Bioética. Tomada de decisões. Poder familiar. Análise ética. Legislação.

## Resumen

### Límites del poder familiar en las decisiones acerca de la salud de sus hijos – directrices

El respecto por el ser humano es uno de los principios fundamentales de la bioética, que se manifiesta a través del ejercicio de la autonomía. Cuando el paciente no tiene competencia para tomar sus propias decisiones en relación a la salud, como es el caso de niños menores de doce años de edad, existe la presunción de que sus padres, a través del ejercicio del poder familiar, decidan por ellos. Lo que queremos discutir es la legitimidad y la justicia de padres decidiendo por sus hijos menores de edad, cuando sus opciones sobrepasan los límites tolerados por la ética, por la ley y por la sociedad en determinadas situaciones y cuál es la práctica usual en el Brasil, cuando hay conflicto de interés entre la propuesta terapéutica del médico y el deseo de los padres.

**Palabras-clave:** Bioética. Toma de decisiones. Responsabilidad parental. Análisis ético. Legislación.

---

**Doutor** [djkipper@pucrs.br](mailto:djkipper@pucrs.br) – Pontifícia Universidade Católica do Rio Grande do Sul, Porto Alegre/RS, Brasil.

## Correspondência

Rua Portuguesa 460/1.101 CEP 90650-120. Porto Alegre/RS, Brasil.

---

Declara não haver conflito de interesse.

Bioethics has developed methodologies that are useful for the discussion and resolution of moral conflicts that arise in the practice of care, and aims to study problems in a rational, systematic and objective manner, so that the decision-making results in good and correct choices <sup>1,2</sup>. Clinical bioethics provides several models for decision-making <sup>3</sup>, and this study aims to use the casuistry procedure described by Albert Jonsen and Stephen Touilmin in 1988 <sup>4</sup> to propose solutions for an example case scenario.

Application of the casuistic method involves analysis of the medical case in question as an ethical problem, based on the topics of <sup>3</sup>: medical indications, patient preferences, quality of life, and economic factors. For each topic, there are questions to guide discussion and analysis of the case. This article is concerned with substitute decisions made by delegation for preadolescent children (under 12 years old), to whom subjective and substituted judgment criteria cannot be applied, as they are legally incapable and from the point of view of cognitive development, incompetent. As a result, only the criteria of greater benefit or best interest can be applied.

This article aims to discuss the legitimacy and justice of parents making decisions on behalf of preadolescent children in situations where there is a conflict of interest between the treatment proposed by the doctor and the wishes of parents. The article intends to consider ethical rather than legal issues, but will use Brazilian and international law as a reference for some points.

## Scenario

A 9-year-old girl has chronic renal failure. After an extensive review of the case and considering the complications already presented in her medical history, the assistant nephrologist, along with his team, indicates kidney transplant to prolong and improve the quality of life. The patient and her parents accept the possibility, but have an exclusion of liability form, which states that they will not permit the transfusion of blood or its derivatives to be used in the treatment, and freeing doctors, the hospital and the hospital staff from any liability that may result from compliance with the document. The form is signed by the patient, by her parents and a witness.

The nephrologist, faced with this problem of conscience, on one hand convinced of his medical opinion, but on the other concerned with assuming the risk of performing the transplant without the

use of blood or its derivatives, seeks the advice of the hospital clinical bioethics committee.

## Discussion of the case scenario by casuistic method

### Medical indications

The patient's doctor describes that – after a thorough assessment of her medical status (irreversible chronic renal failure) and history (several events that put her at risk of premature death), taking into account quality of life (three weekly hemodialysis sessions and resulting travel, with associated discomfort and cost), limited mobility, possible hospital stays, the standard medical conduct in these situations (with wide support in available literature) and the lower average period of survival for hemodialysis patients (10-15 years) than for transplant patients – renal transplantation from a cadaveric donor was recommended. The doctor believes that this therapeutic proposal presents more benefits for the patient than the risks to which she is subjected by maintaining the current approach. He feels uncomfortable, however, with the refusal of the patient and her parents to receive, if necessary, blood or blood derivatives. He knows that he should propose the transplant, but is concerned about the risk of performing it without having all the therapeutic resources available to him, even after explaining the situation fully to the patient and her parents.

### The choice of the patient

One of the fundamental principles of bioethics is that competent adults have the right to decide over their own bodies, and that the doctor must obtain the free and informed consent of the patient before performing any action <sup>5-10</sup>. Incapable patients have the same rights as capable patients, although the form of exercising these rights is necessarily different <sup>10</sup>. It is based on the principle of respect for persons, also known as the principle of autonomy.

The ethical standard for substitute decisions was the *Patient Self-Determination Act* <sup>11</sup>, whose guidelines include, in this order:

- Subjective criterion - the patient decides, when able or through direct (living wills) or indirect (power of attorney) advance directives, how he or she shall be treated when incapable and when others must act in his or her place.
- Substitute judgement criterion - a substitute chooses what the patient would wish if he or she

was competent and aware both of the medical options and his or her real clinical situation, including the fact of being incompetent.

- Greater benefit or best interest criterion - a substitute decides, in his or her opinion, what best promotes the interests of the patient and what would provide he or she with the greater benefit.

Brazilian law is also explicit in relation to the need to obtain the free and informed consent of the patient in any medical procedure, except in cases of imminent risk of death<sup>12-15</sup>.

### **Competence to personally exercise the activities of civil life**

The patient in the case scenario is 9 years old and in accordance with the Brazilian Civil Code<sup>12</sup>, is *absolutely incapable of personally exercising the activities of civil life*, meaning that it falls to her parents to decide for her, in the exercise of parental authority, using the criterion of “greater benefit” or “best interest” which, by law and ethical assumption, is decided by the parents. The door to the extremely complex world of decisions by delegation is thus opened, and the immediate problem that presents itself is: *To what extent do parents have the right to decide for their children?*<sup>16</sup>

Buchanan and Brock define “best interest” as *acting so as to promote maximally the good of the individual*<sup>17</sup>, and Beauchamp and Childress<sup>18</sup> as *when a substitute in decision making should determine the widest network of benefits between the options, designating different weights to each option and discounting or subtracting the risks and costs involved*. In both views, it is required that the substitute always act in a way so as to choose what is more favorable to the child.

### **Arguments for the presumption of the autonomy of parents**

There are good reasons for the presumption of respecting the autonomy of parents and the privacy of the family:

- Most parents are motivated by the best interests of their children, want what is best for them and make decisions that are beneficial to them<sup>19</sup>;
- The motivation of the welfare of their children leads parents to make the best choice for them<sup>20</sup>;
- Parents have privileged insight into the preferences and capabilities of their children, due to their proximity to them;

- The support of parents has medical significance, improving patient recovery;
- The interests of family members sometimes come into conflict, and loved ones may be hurt as a result of certain decisions. Parents are usually better positioned than people outside the family to evaluate the competing interests and make the best decision;
- Parents should have the right to see their children grow up in accordance with their own standards and values and to transmit these to them;
- So that intra-family relationships can flourish, the family must have sufficient space and be free from other intrusions. Without autonomy to make decisions, including the choice of religion, families do not flourish, and their important role in society will suffer;
- The burdens of the consequences should be borne by the family<sup>21</sup>;
- Parents have natural authority over their children;
- It is reckless to refute the choice of the parents without absolute certainty of the prognosis of the proposed intervention;
- The discomfort caused by court orders is detrimental to society and to other parents, as it compromises the doctor-patient relationship<sup>22</sup>;
- Pragmatically, (a) if we do not respect the right of parents to decide for their children, we run the risk of them not bringing them to medical care in the first place<sup>20</sup> and; (b) time is lost before treatment can begin<sup>23</sup>.

### **Questions regarding the presumption of the rights of parents**

Dare<sup>20</sup> casts doubt over the majority of the arguments in favor of the presumption of the authority of parents to make decisions on behalf of their children. In summary, his arguments are as follows:

#### **Parents are motivated by the best interests of their children**

- Even if this were true, it does not imply that others, such as health professionals, are also not motivated by the best interests of their patients;
- Motivated by the right reasons, but medically ignorant or inexperienced, parents may simply be confused as to what are the best interests of their child;

- Parents may have interests that conflict with the interests of the child, for example, the best interests of the family as a whole or the best interests of another child.

#### **Parents know best the interests of the child**

- When it comes to the interests of the child, the question is what is good or best for him or her. However, what is good for the child involves complex medical judgements, which parents are unlikely to be able to perform. What parents know best are the desires, preferences and short-term consequences;
- Even so, due to the asymmetrical relationship between parents and children, this knowledge is unlikely to be authentic. Even if the child had such a skill, he or she would not have the cognitive maturity to think about future consequences, especially if the intervention is traumatic or painful. The older the child is, the greater parental knowledge about his or her preferences will be;
- Consideration should be given the ability that parents know the tolerance of their children to pain. But again, this may focus more on present than future harm;
- Finally, one must consider the stress suffered by parents when their child is ill, something that can affect their decisions. While doctors are often surprised by the tolerance of children to painful or uncomfortable procedures, parents may be even more surprised.

#### **The support of parents has medical significance**

- While this is true, provided there is a good relationship and effective communication between parents and child, parents continue to care properly for their children, even when their decisions are refuted;
- Although parents and family must bear the burdens of medical interventions, this has no direct relationship with the best interests of the child. What matters is the prognosis, doing good for the child and not doing harm.

#### **Religious argument**

When the religion of parents interferes with the health care of children, the concern of doctors should be with the third party (the child). Everyone has the right to choose their religious preference, but not to make martyrs of their children. In addition, the child must also have the right to choose his

or her own religion, when he or she has the power to make autonomous decisions. But for that he or she needs to survive.

#### **Doubts and certainties regarding treatment**

Some argue that it is not advisable to challenge the family about decisions when unsure about the diagnosis or prognosis. But even though unsure of a diagnosis, health professionals may still need to act. Furthermore, does a permanent truth really exist in science? A prognosis is a probabilistic calculation based on similar previous situations, in an attempt to predict the future – but is always uncertain.

In summary, one cannot deny that parents have a natural authority over children. In the past, they would choose husbands or wives, deliver a daughter's dowry, or physically punish their children. Were they right then? In this particular case, one argument that can genuinely not be refuted is pragmatic: the risk that parents will not bring their children for treatment if they are not given the right to determine what treatment will be carried out. This stimulates the search for ways to align practical needs with defensible theoretical conclusions<sup>20</sup>.

#### **“Best interest” or “least harm”?**

Diekema<sup>5</sup> considers that, although the criterion of best interest is the legal and ethical standard to determine when state intervention is justified, it is not useful for the standards currently adopted by doctors and judges, as it is difficult to implement and offer little practicality. The author proposes the use of the principle of non-maleficence or harm and presents the following four reasons.

First, it is difficult to precisely define the best interests of the child, and attempts to do so can generate controversy. Best interest is more easily applied in situations where the child's life is at risk, and where the danger can be prevented with easy, safe and effective measures. For this reason, there is little controversy about the use of blood transfusion when recommended in a situation of risk. However, in situations where risks are lower, such as in the repair of a cleft palate, it is difficult to be sure if the refusal of parents violates the standard.

Second, the notion of “best interests” is intrinsically a question of values, and many parents consider their choices coincide with the best interests of the child. For example, for a Jehovah's Witness, turning one's back on eternal life alongside the Creator is hardly a trivial consequence of accepting a recommendation of medical transfusion.

In this case, there is a conflict between what parents consider “best interest” and what the doctor believes. There is no objective “best interest”, but a question of values.

Thirdly, the nature of the interest is usually complex. Although medical considerations are important, the interests of the child may also be affected by the emotional or physical consequences that accompany the chosen action. Best interests are too often reduced to only medical purposes. For example, when receiving chemotherapy, the concern of the medical professional is with the possibility of improving quality of life and curing the cancer. Parents, meanwhile, may worry more about the negative effects of chemotherapy and wonder whether so much suffering for a possible cure is worth it.

Finally, it is not clear if the best interests of the child refer always and solely to his or her health <sup>24,25</sup>.

While parents have certain presumed rights, Whitney <sup>21</sup> notes that their ethical and legal authority over the health care of their children stems from a responsibility to promote the best interests of the child’s health.

### Quality of life

Evidence-based medicine recommends kidney transplant in cases of chronic renal failure of patients dependent on hemodialysis, if there are no comorbidities that contraindicate this treatment <sup>26,27</sup>.

### Conjectural factors

Conjectural factors are the social, legal and institutional circumstances involved in the case, or in other words, its context. The following guiding questions should be considered in the case scenario:

- Are family matters unduly influencing treatment decisions?
- Are religious or cultural factors influencing the choices?
- Are there legal implications, depending on the treatment option?

The answer to the three guiding questions is yes.

### Family matters and religious factors

The parents, who are Jehovah’s Witnesses, refuse to accept the transfusion of blood or blood derivatives because of a literal interpretation of the Holy Scriptures (Bible) <sup>28</sup> in Genesis 9: 3-4, Leviticus

7:26, 1 Samuel 14:32,33 and Acts 15:28,29. They do not accept blood collected by autologous preoperative donation because, for them, blood should not be removed and stored. There are variations between Jehovah’s Witnesses communities as to which blood derivatives should be accepted <sup>29,30</sup>.

### Legal implications of treatment decisions

The next question that was presented was: would meeting the family’s wishes, if transfusion is necessary to prevent death or serious and irreversible harm to the patient, have legal implications?

### Well-being of children versus autonomy of parents

The patient in the case scenario, who is under 12 years old, is considered civilly incompetent to make decisions regarding her health <sup>12</sup>, and her parents are “empowered” to do so in her place, because of parental power <sup>12</sup>. A conflict exists where parents, due to their religious choices, interfere with medical advice and the best interests of the patient, considering that the refusal of any blood transfusion may result in severe harm.

Although it is presumed under law and ethics that parents take priority when making decisions on behalf of their children, there are situations where it is up to doctors to challenge this primacy, in order to have recourse to the best procedures, personnel and technicians available to treat the patient <sup>22</sup>, subject to duty of care established by the legal system <sup>25</sup>.

As parental authority is not absolute, when the choice is contrary to the best interests of the child, the state can intervene, acting in accordance with the *parens patriae* doctrine <sup>31</sup> (which in Latin means father of the country). In law, this refers to the power of the state to use surveillance and intervene against an abusive or neglectful father and to act as the “father” of any child or person in need of protection <sup>12,31,33</sup>. According to the US Supreme Court, in the case of *Prince vs. Massachusetts*, *neither the rights of religion nor parenthood are beyond this limitation* <sup>33</sup>. Brazilian law is explicit in this respect, in Article 227 of the country’s Constitution <sup>34</sup> and Article 13 of the *Statute of the Child and Adolescent (SCA)* <sup>35</sup>. In addition to these, several other national and international legal instruments recommend this conduct <sup>14,35-37</sup>.

However, simply obtaining a court order, without giving due weight to the position of the parents and without exhausting all dialogical options, can

cause excessive harm to the family unit and the children<sup>23</sup>. Kopelman and Deville<sup>38</sup> argue that the coercive interference of the state in the prerogatives of parents, for the good of society and children, is justified when there is convincing evidence that the actions or decisions of parents represent serious risk to children. Moreover, Sher<sup>39</sup> points out that negligence, the basis of the state's action in many health care cases, has been defined as *the failure to provide a minimum quality of care that the community can tolerate*<sup>38</sup>.

The requirements of these authors for state intervention is not an overworked standard of best interest, but rather a model based on harm. Therefore, the fundamental question does not seem to be how to identify the alternative that best represents the interests of the child, but the limit below which parental decisions cannot be tolerated. Diekema<sup>5</sup> supports the idea that the principle of harm is the legal and ethical basis for such intervention. He warns that the principle is consistent with the limits suggested by the majority of authors and applied by the majority of courts.

### **The principle of harm and state intervention**

The authority of the state in health comes primarily from its constitutional established monitoring role to protect public health, welfare and safety. The ethical basis for the exercise of this power is based on what is known as the principle of harm or non-maleficence. John Stuart Mill, quoted by Diekema<sup>40</sup>, argues that *the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant*<sup>40</sup>.

Joel Feinberg, also cited by Diekema<sup>41</sup>, refined this concept, arguing that, *to be justified, the restriction of individual liberty must be effective to prevent the damage in question, and that there should be no option less intrusive for individual freedom that is also effective in preventing the damage*.

The principle provides the basis to identify the threshold for state intervention. The characteristic of parental decision which justifies intervention is not that which is contrary to the best interests of the child, but that which causes the child harm or damage. The authorities will then legitimize intervention in two situations, both of which fulfil the criteria of the principle of harm: 1) the intervention should be based on the doctrine of *parens patriae*<sup>31</sup>, that is, the state has the authority to protect and care for those who cannot protect and care for themselves,

and may intervene when there is evidence that parents' decisions can cause harm to their children; 2) the intervention can be justified as an exercise for monitoring the health protection of the population or population groups.

The doctrine of the power of the state recognizes that society has an obligation to ensure that its most vulnerable members have access to basic needs. Parental decisions are usually accepted, except when they result in substantial risk of severe harm. The American Academy of Pediatrics<sup>37</sup> argues that state intervention should be a last resort, recommended only when the treatment refused can prevent substantial damage, injury or death. When state action is determined, a series of eight questions suggested by Diekema<sup>5</sup> must still be answered: 1) By refusing the proposed procedure, are parents are putting the child at risk of significant harm?; 2) Is the risk of harm imminent, and is immediate action required to prevent it?; 3) Is the intervention that has been refused needed to prevent harm?; 4) Is the effectiveness of the refused intervention proven and is it therefore able to prevent the harm?; 5) Does the refused intervention place the child at high risk of harm, and are its benefits much greater than the alternative chosen by parents?; 6) Is there another option, which interferes less in the autonomy of parents and is therefore more acceptable to them, and which could prevent the harm to the child ?; 7) Can state intervention be generally applied to all other similar situations?; 8) Would most parents agree that state intervention was reasonable? The case scenario in question easily meets the eight conditions.

Acting as a guardian of the general interests and well-being of children, the state, as *parens patriae*, can restrict parental control by ordering medical treatment at school, regulating or defining child labor, and many other situations. The laws on child abuse expressly recognize that parental rights are not absolute. If parents refuse to provide a child with necessary care, the state may take temporary custody in order to authorize basic medical care, using the argument that the health care provided by the parents for the child, or the lack of it, is negligent.

The most common and compelling argument used by parents to oppose state intervention is that people are free to practice their religion. However there is an essential difference between the right to make a religious choice (freedom of conscience) and to practice a religion (freedom of action). While the violation of the first is never justified in a free society, the latter is inconsistent in a community that rejects the initiation of force among its members.

Freedom of action, where it causes harm to others, as is true in the case scenario considered here, indicates that the right to practice a religion does not include the freedom to expose the community or a child to illness or death<sup>23</sup>. In other words, the right of a person to practice their religion is superseded by the right to life of another<sup>20</sup>.

### Points that reinforce the arguments of the state

According to Horn<sup>19</sup>, doctors have the interests of children as a paradigm and cannot assume in advance that all involved, even the parents, have only those interests as a priority. Though imbued in the welfare of their children, parents have a limited ability to understand the medical context involved, may give excessive weight to the child's suffering in the short term at the expense of long-term benefits, and, moreover, are submerged in the emotion of the situation, while the state, represented by the courts, is invariably more objective in its ability to make decisions<sup>23</sup>.

The fact that the family are the only people to suffer from the death of a child does not support discussion of the value of his or her life. If a child, in order to have a positive prognosis, requires great attention and care following medical intervention, some weight should be given to parental decisions. However, the prognosis itself, rather than the need for intensive post-intervention care, should not be a deciding factor. It is assumed that children recover better when they have family support, but that does not mean that parents whose treatment options are rejected do not take good care of their children following medical intervention<sup>5</sup>.

What is the nature of the privileged information that parents hold, and its medical significance? A close relationship with a child may result in a bias for the feelings of one in relation to the other, such as guilt, helplessness, hope or despair or even unwillingness to disagree. To obtain a more impartial notion of the reality of the situation, one must reflect on what a reasonable adult would do<sup>5</sup>.

While undermining the autonomy of parents will have social repercussions, other interests must be recognized. First, the value of human life; second, the protection of innocent parties, who do not have the ability to defend themselves; third, the maintenance of a productive and self-perpetuating society<sup>24</sup>. It can be argued that if the state is not the advocate of a child's well-being against the wishes of his or her parents, the damage caused to society will not be slight.

It is the duty of the doctor to argue that a decision in favor of a technically invalid substitution goes against standard medical conduct and his or her commitment to defend the values of beneficence, non-maleficence and of justice.

Finally, state intervention is valid in circumstances in which, due to the severity and urgency of the medical situation of the patient, treatment needs to be performed before such intervention can be approved by a deliberative and shared process.

However, it is never recommended, except where unavoidable, to seek a court order without giving due weight to the position of the parents and without exhausting all dialogical positions<sup>23</sup>. The imposition of law among the values and wishes of parents and their children is a delicate matter, which requires extensive consideration. In the case of rejecting such a sacred principle as the primacy of parents as guardians of their children and those delegated to make decisions for them, the burden of proof is on the party that was chosen to refute it<sup>25</sup>.

According to Beauchamp and Childress<sup>18</sup>, in order to legitimize the violation of a *prima facie* rule to follow another path, it is necessary:

- To offer better arguments for the approach that prevailed than for that which has been broken. The justification may be that a child's life is more important than a set of desires or moral values. Here it is not the morale of the child that is under discussion, but the parents. The child deserves the chance to grow and make his or her own religious choices;
- That the moral purpose that justified the infraction has a real chance of being reached;
- That no morally preferable alternative action can be found;
- That the selected form of infraction is the only possible way of achieving the benefit sought by the action;
- That the offending agent will seek to minimize the negative effects of the infraction.

### The ethical problem

Now the ethical problem is clear: on the one hand, from a medical and legal point of view, blood transfusion may be obligatory, and necessary to avoid the serious and irreversible harm or the death of the patient; on the other, the parents refuse to allow their daughter to undergo blood transfusion.

**Blood transfusion**

The literature cites the benefits associated with blood transfusion<sup>42</sup> as the removal of the harmful effects of severe anemia in the postoperative period, a situation proven in patients who refused blood transfusions for religious reasons<sup>43</sup>. If the hemoglobin (Hb) levels between 7 and 8g/dL do not appear to have deleterious effects on mortality, the risk of death increases when Hb drops to less than 7g/dL. This risk is 2.5 times greater for each gram of Hb/dL less, and reaches 64% at levels equal to or lower than 3g/dL. Death does not usually occur immediately<sup>44</sup>. A later study found a 50% mortality rate within thirty days after surgery, with levels equal to or less than 3 gdl, among hospitalized patients, suggesting an improvement in the management of patients who refuse blood transfusion<sup>45</sup>.

A number of risks can be identified, from infection to immune problems. Two topics stand out: 1) randomized studies show differences between liberal transfusion practices and restrictive practices, with better results in the latter<sup>44</sup>; 2) randomized studies show old blood, rather than fresh blood, increases morbidity and mortality<sup>44</sup>.

Considering the above, and because it was not an emergency situation, the Clinical Bioethics Committee provided the following recommendation in the clinical case under discussion:

- Increase engagement with the parents of the patient. It is important to have an open mind and involve parents in the debate, to understand their reasons, their arguments and their desires. It is not just any choice that the parents are making of their daughter. It is the choice between a limited earthly life, and eternal life with the Creator. They may feel pressured to fulfill their ethical values, and in this case are imagining their daughter being rejected by the community, leading eventually to the abandonment of treatment.
- In a private meeting, guarantee confidentiality and privacy. Thus, everyone will have the opportunity to express themselves, without pressure or coercion. The benefits and risks of transfusions should be discussed again, so that parents are well informed. Despite the problem at hand, the doctor should explain his obligation to provide the best possible care, which is consistent with the values and preferences of parents and the patient.
- Share the decision. Check that the patient and family understand what – exactly – they under-

stand will happen if blood and blood derivatives are not received. There should be a clear plan for what will happen in a worst case scenario, when a decision will have to be made between transfusion, severe morbidity or death. Some patients accept transfusion in this situation.

- Reveal the concerns and the discomfort of the doctor in a transparent fashion. The doctor may not feel comfortable with the patient's choices, and also may not have the expertise to deal with the situation. In this case, the patient, who requires urgent treatment, can be referred to another medical professional who is willing to accept the case. The withdrawal of care in these cases is ethically acceptable and is not professional malpractice provided the doctor finds another medical professional to care for the patient.

The doctor should make clear that, in the event of a situation in which the life of a minor is at risk, there is no need for a court to authorize transfusion. It should be explained to the family that this is a legal duty<sup>45</sup>. Judges in such cases should have the sensitivity not to accuse parents, taking power from the family only for transfusion, and not for other decisions that parents may take that will not bring harm to the patient<sup>46</sup>.

**Back to the Clinical Bioethics Committee**

Despite the recommendations of the Committee, the ethical problem remains the same. The parents, because of the bonds that have developed with the institution and the doctor, would prefer not to be referred to other medical professionals and other institutions. The doctor, in turn, has explained that he will do everything in his power to prevent the transfusion, including: a) suitable preoperative preparation and management of the patient; b) discussing the case with a professional who has had similar experience; c) during the intraoperative and postoperative period, reducing maximum blood loss, maximizing the supply of O<sub>2</sub> and reducing its consumption; using blood substitutes, if available; having a contingency plan, not taking the decision to transfuse alone; and in the worst case scenario, sharing the decision with the anesthetist and the assistant surgeon.

Given the above, the Clinical Bioethics Committee proposed the following courses of action:

- Provide parents, through the attending physician, the option of referring the patient to another medical professional who agrees to perform the transplant without blood transfusion;



- Perform the transplant at the institution and, through the local social service, request judicial authorization for transfusion if necessary, despite all the proposed protective measures;
- Assure parents that the authorization be limited to any transfusion of blood or blood derivatives and that all other options will be considered to the maximum extent possible, whilst ensuring that confidentiality and privacy will be respected. All resolutions must be recorded in the medical history of the patient.

## Discussion

The loss of parental autonomy can have a major impact on the family unit, but, after considering the arguments, it is clear that in the current social context, children's rights should be protected by state intervention when the decisions of parents exceed society's limit of tolerance in relation to the possibility of causing harm to a child. This is beneficial, yet still expensive for the community and individuals.

Although the religious practices of parents should be considered secondary when evaluating the best interests of the child, appropriate weight should be given to the beliefs of parents and the impact of decisions on the family unit in the context of judicial decisions. It is also important to limit automatic and arbitrary restrictions on state intervention in the autonomy of parents, and give due weight to an individualized approach to patients, mainly because of the diversity of views on different aspects of transfusion.

Experience shows that religious communities rarely refuse to take care of transfused children, and parents often feel relieved after the decision has been taken from their hands, allowing them to refuse the transfusion and still have their child treated<sup>47</sup>. A minimum intervention by the state is justified only in cases where medical opinion unanimously considers that taking no action will result in serious and irreparable harm or death, and where life after the intervention will be of sufficient quality to justify the treatment<sup>23</sup>.

## Guidelines to accepting or refuting parental power in health

### *Irrefutable Premises*

Bioethical deliberation stems from the fundamental principle of respect for human beings,

considered to be an irrefutable premise<sup>2</sup>. All who have an interest in the case should participate as valid moral actors, exposing their rational arguments and justifying them morally. Everyone should have an understanding and tolerant attitude to divergent values and positions.

### *Guidelines and recommendations*

The proper understanding and analysis of ethical problems requires the careful presentation of the medical case so that those involved clearly understand the options available. The medical history is the support material for the problem to be analyzed, which should be fully known and understood to reduce areas of uncertainty in the deliberations.

Parents are "empowered" by parental power to decide for their children. The patient's consent should be considered from 6 years of age and upwards, provided that the child's ability to assess his or her problem has been identified by the medical team. The free and informed choice of parents is of ethical, legal, medical and psychological importance, as their preferences form part of the nucleus of the clinical relationship and should be taken into account, provided they do not exceed the limits tolerated by ethics, the law and the community.

In the case of a procedure designed to preserve life (imminent risk of death), it is legally permissible and universally accepted that consent can be presumed<sup>48</sup>. The lower the risk-benefit balance, the more the medical option should be considered, and vice versa; the greater the risk-benefit balance, the more the choices of the parents should be considered.

When the prognosis is good, the best interest argument prevails. When it is bad, the wishes of the parents will prevail<sup>49</sup>. The older the child and the lower the risk-benefit balance, the more the child's consent should be considered.

When there are conflicts between medical options and parental decisions, the discussion should be widened to involve other family members, church representatives and/or other representatives chosen by parents and/or the clinical bioethics committee of the institution, if any. If the conflict persists, and where the parental choice could cause the serious irreparable harm or death of the child, and there is no imminent risk of death, one must resort to a court decision, which is always the last resort<sup>48</sup>. It must also be ensured that confidentiality and privacy will be respected, and the entire process should be registered in the medical history of the patient.

## Referências

1. Loch JA, Gauer GJC. Comitês de bioética: importante instância de reflexão ética no contexto da assistência à saúde. *Rev AMRIGS*. 2010;54(1):100-4.
2. Loch JA. Metodologia de análise de casos em bioética clínica. In: Loch JA, Gauer GJC, Casado M, organizadores. *Bioética, interdisciplinaridade e prática clínica*. Porto Alegre: EdiPUCRS; 2008. p. 367-75.
3. Zoboli E. Tomada de decisão em bioética clínica: casuística e deliberação moral. *Rev. bioét. (Impr.)*. 2013(3): 389-96.
4. Jonsen AR, Toulmin SE. *The abuse of casuistry: a history of moral reasoning*. Berkeley: University of California Press; 1988.
5. Diekema DS. Parental refusals of medical treatment: the harm principle as threshold for state intervention. *Theor Med Bioeth*. 2004;25(4):243-64.
6. Merrick JC. Christian Science healing of minor children: spiritual exemption statutes, first amendment, and fair notice. *Issues Law Med*. 1994 inverno;10(3):321-42.
7. Goldim JR. Princípio do respeito à pessoa ou autonomia. [Internet]. 2004 [acesso 24 jan 2014]. Disponível: <http://www.bioetica.ufrgs.br/autonomi.htm>
8. Ubel PA. The challenge of measuring community values in ways appropriate for setting health care priorities. *Kennedy Inst Ethics J*. 1999;9(3):263-84.
9. Tauber AI. Medicine, public health, and the ethics of rationing. *Perspect Biol Med*. 2002;45(1):16-30.
10. Meisel A. The legal consensus about forgoing life-sustaining treatment: its status and its prospects. *Kennedy Inst Ethics J*. 1992;2:309-45.
11. Clotet J. Reconhecimento e institucionalização da autonomia do paciente: um estudo da The Patient Self-Determination Act. *Bioética*. 1993;1(2):158-64.
12. Brasil. Código Civil. Lei nº 10.406, de 10 de janeiro de 2002. [Internet]. 2002 [acesso 22 jan 2015]. Disponível: [http://www.planalto.gov.br/ccivil\\_03/leis/2002/l10406.htm](http://www.planalto.gov.br/ccivil_03/leis/2002/l10406.htm)
13. Brasil. Código Penal. Decreto-lei nº 2.848, de 7 de dezembro de 1940. [Internet] 2003 [acesso 22 jan 2015]. Disponível: [http://www.planalto.gov.br/ccivil\\_03/decreto-lei/del2848.htm](http://www.planalto.gov.br/ccivil_03/decreto-lei/del2848.htm)
14. Conselho Federal de Medicina. Código de Ética Médica. Resolução do Conselho Federal de Medicina nº 1.931/2009. *Diário Oficial da União*, 24 set 2009, Seção I, p. 90; retificação *Diário Oficial da União*, 13 out 2009, Seção I, p. 173.
15. Brasil. Código de Defesa do Consumidor. Lei nº 8.078, 11 set 1990. [Internet] 2003 [acesso 22 jan 2015]. Disponível: [http://www.planalto.gov.br/ccivil\\_03/leis/l8078.htm](http://www.planalto.gov.br/ccivil_03/leis/l8078.htm)
16. Kipper DJ. Até que ponto os pais têm o direito de decidir por seus filhos. *J. pediatr*. 1997;73(2):67-74.
17. Buchanan AE, Brock DW. *Deciding for others: the ethics of surrogate decision-making*. Nova York: Cambridge University Press; 1990. p. 234-7.
18. Beauchamp TL, Childress JF. *Principles of biomedical ethics*. 5ª ed. Nova York: Oxford; 2001. p. 93-126.
19. Horn C. Religion, blood transfusions, and childrens' rights. [Internet]. 2013 [acesso 27 jan 2014]. <http://www.hmcwriter.com/religion-blood-transfusions-and-childrens-rights/>
20. Dare T. Parental rights and medical decisions. *Paediatr Anaesth*. 2009;19:947-52.
21. Whitney SN, Ethier AM, Frugé E, Berg S, McCullough LB, Hockenberry M. Decision-making in pediatric oncology: who should take the lead? The decisional priority in pediatric oncology model. *J Clin Oncol*. 2006 1 jan;24(1):160-5.
22. Wilson P. Jehovah's Witness children: when religion and the law collide. *Paediatr Nurs*. abr 2005;17(3):34-7.
23. Kopelman LM. Children and bioethics: uses and abuses of the best-interests standard. *J Med Philos*. 1997;22(3):213-7.
24. Humphrey T. Children, medical treatment and religion: defining the limits of parental responsibility. *Austr J Human Rights*. 1998; 14(1):141-69.
25. Hickey KS, Lyckholm L. Child welfare *versus* parental autonomy: medical ethics, the law, and faith based healing. *Theor Med Bioeth*. 2004;25(4):265-76.
26. Romão Junior JE. Insuficiência renal crônica. In: Cruz J, Praxedes JN, Cruz HMM. *Nefrologia*. São Paulo: Sarvier; 1995. p. 187-200.
27. Associação Médica Brasileira. Projeto Diretrizes. *Transplante renal: indicações e contraindicações*. [Internet]. [acesso 7 fev 2014]. Disponível: [http://www.projetodiretrizes.org.br/volume\\_4.php](http://www.projetodiretrizes.org.br/volume_4.php)
28. Bíblia. São Paulo: Sociedade Bíblica Católica Internacional/Paulinas, 1990.
29. Watch Tower Bible and Tract Society of Pennsylvania. Rightly, value your gift of life. [Internet]. 2004 [acesso 8 fev 2014]. Disponível: <http://wol.jw.org/en/wol/d/r1/lp-e/2004444>
30. Crookston KP. The approach to the patient who refuses blood transfusion. *UpToDate*. [Internet]. dez 2004 [acesso 13 nov 2013]. Disponível: <http://www.uptodate.com/contents/the-approach-to-the-patient-who-refuses-blood-transfusion/abstract/4>
31. Wikipédia. *Parens Patriae* [verbete]. [acesso 10 fev 2014]. Disponível: [http://en.wikipedia.org/wiki/Parens\\_patriae](http://en.wikipedia.org/wiki/Parens_patriae)

32. Tillett J. Adolescents and informed consent: ethical and legal issues. *J Perinat Neonatal Nurs.* 2005;19(2):112-21.
33. US Supreme Court. *Prince v. Massachusetts*, 321 US 158. Justia US Supreme Court. [Internet]. 1994 [acesso 22 jan 2015]. Disponível: <https://supreme.justia.com/cases/federal/us/321/158/case.html>
34. Constituição da República Federativa do Brasil. Brasília: Senado Federal; 1988.
35. Brasil. Estatuto da Criança e do Adolescente. Lei nº 8.069, de 13 de julho de 1990. Disponível: [http://www.planalto.gov.br/ccivil\\_03/leis/l8069.htm](http://www.planalto.gov.br/ccivil_03/leis/l8069.htm)
36. Brasil. Decreto nº 99.710, de 21 de novembro de 1990. Promulga a Convenção sobre os Direitos da Criança. [Internet]. 1990. [acesso 22 jan 2015]. Disponível: [http://www.planalto.gov.br/ccivil\\_03/decreto/1990-1994/D99710.htm](http://www.planalto.gov.br/ccivil_03/decreto/1990-1994/D99710.htm)
37. American Academy of Pediatrics. Committee on Bioethics. Religious objections to medical care. *Pediatrics.* 1997;99(2):279-81.
38. DeVille KA, Kopelman LM. Fetal protection in Wisconsin's revised child abuse law: right goal, wrong remedy. *J Law Med Ethics.* 1999;27(4):332-42.
39. Elizabeth J. Sher EJ. Choosing for children: adjudicating medical care disputes between parents and the State. *NYU Law Rev.* 1983;58:176-7.
40. Diekema DS. Op. cit. p. 250.
41. Diekema DS. Op. cit. p. 250.
42. Carson JL, Noveck H, Berlin JA, Gould AS. Mortality and morbidity in patients with very low postoperative Hb levels who decline blood transfusion. *Transfusion.* jul 2002;42(7):812.
43. Tobian AA, Ness PM, Noveck H, Carson JL. Time course and etiology of death in patients with severe anemia. *Transfusion.* 2009;49(7):1.395-9.
44. Jo KI, Shin JW, Choi TY, Park YJ, Youm W, Kim MJ. Eight-year experience of bloodless surgery at a tertiary care hospital in Korea. *Transfusion.* 2013 May;53(5):948-54.
45. Rogers DM, Crookston KP. The approach to the patient who refuse blood transfusion. *Transfusion.* set 2006;46(9):1.471-7.
46. Frankel LS, Damme CJ, Van Eys J. Childhood cancer and the Jehovah's Witness faith. *Paediatrics.* 1977 dez;60(6):916-21.
47. Muramoto O. Recent developments in medical care of Jehovah's Witnesses. *West J Med.* 1999;170(5):297-301.
48. Hirschheimer RM, Constantino CF, Oselka GW. Consentimento informado no atendimento pediátrico. *Rev Paul Pediatr.* 2010;28(2):128-33.
49. Talati ED, Lang CW, Ross LF. Reactions of pediatricians to refusals of medical treatment for minors. *J Adolesc Health.* 2010;47(2):126-32.

